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Factors associated with the quality of life of family carers of people with dementia: a systematic review

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ABSTRACT

INTRODUCTION: Family carers of people with dementia are their most important support in practical, personal and economic terms. Carers are vital to maintaining the quality of life (QOL) of people with dementia. This review aims to identify factors related to the QOL of family carers of people with dementia.

METHODS: Searches on terms including 'carers', 'dementia', 'family' and 'quality of life' in research databases. Findings were synthesised inductively, grouping factors associated with carer QOL into themes.

RESULTS: 909 abstracts were identified. Following screening, lateral searches and quality appraisal, 41 studies (n=5,539) were included for synthesis. Ten themes were identified: demographics; carer-patient relationship; dementia characteristics; demands of caring; carer health; carer emotional wellbeing; support received; carer independence; carer self-efficacy; and future.

DISCUSSION: The quality and level of evidence supporting each theme varied. We need further research on what factors predict carer QOL in dementia and how to measure it.

Keywords: Quality of life, family carers, family carergivers, informal carers, dementia, measurement Alzheimer's disease, systematic review

1. 1. BACKGROUND

Dementia is one of the most common and serious disorders we face. It is a global issue; 46 million people have dementia and it costs over \$600 billion (£450 billion) per year [1,2]. The numbers with dementia will double and costs at least triple in the next 20 years [1,2]. Dementia causes irreversible decline in cognitive, social and physical function. Abnormalities in behaviour, insight and judgement, anxiety and depression are all part of the disorder [3].

The National Dementia Strategy for England [3] identifies family carers as “the most valuable resource for people with dementia”, with 600,000 family carers providing £8 billion (\$11 billion) per annum of unpaid dementia care in the UK alone. Family carers are a vital determinant of positive outcomes for people with dementia, for example, having a co-resident carer exerts a 20-fold protective effect on risk of institutionalisation [4]. In this review, the term ‘family carer’ is used to encompass all informal carers (i.e. family and friends/neighbours) of a person with dementia who provide support. This is the term that our consultation with carers supported most, with ‘carer’ preferred to ‘carergiver’ and ‘family’ preferred to ‘informal’ (even given that this group may include non-family members such as neighbours and friends) in distinguishing family carers from ‘paid’ or ‘formal’ carers .

Caring extends beyond hands-on care to include: anticipating future support needs, monitoring and supervising, preserving the individual’s sense of self, and helping the individual to develop new and valued roles [5]. The challenges of caring are significant. Fifty percent of those with dementia in the community receive 35+ hours of family care per week [6]. Caring in dementia may be complicated by resistance to care, agitation, and/or a lack of insight on the part of the person with dementia into their own needs [6]. Many family carers of people with dementia are older themselves, physically frail with health conditions of their own. Dementia is a progressive, terminal disorder and caring is not a fixed set of experiences, but evolves in a “caregiving career” [7]. The main responsibility for

day-to-day care tends to fall to one family member, usually a woman (in order of likelihood: spouse, daughter, daughter-in-law, son, other relative, and non-relative) [7,8]. While for many there is personal satisfaction derived from caring, the experience can also be detrimental, physically, psychologically and financially [3,8]. Family carers of people with dementia have more anxiety, stress and depression than non-carers and caring for someone with dementia has more negative impacts than caring for other disorders [9,10] with depression occurring in a third of carers of those with dementia [11]. Without the work of family carers, the formal care system would collapse; supporting family carers is therefore a national and international policy priority.

Given that family carers of people with dementia are such an important resource, it is important to ensure that their own Quality of Life (QOL) is satisfactory. Where we use the World Health Organisation definition of QOL as the evaluation by an individual of their position in life, assessed in the context of one's culture, values, goals, expectations, standards and concerns. Factors influencing QOL include the person's physical health, psychological state, level of independence, social relationships, personal beliefs and environmental supports. A necessary first step in monitoring and acting to improve QOL is to determine what good QOL looks like in this population. Whilst there are number of reviews that have touched upon factors that may impact upon QOL in carers of people with dementia [12–14] there is no systematic review of this literature. This is a topic that has been identified as needing research attention [15].

2. AIM

The study aim is to complete a systematic review of the quantitative and qualitative literature to identify factors that affect the QOL of family carers of people with dementia.

3. METHODS

3.1. Protocol and registration

The methods of this systematic review have been developed in accordance with the recommendations from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA) statement [16]. The protocol has been registered in the International Prospective Register of Systematic Reviews (PROSPERO) - CRD42015029462.

3.2. Literature search

Quantitative, qualitative and mixed-methods studies, published in English, were searched using accepted systematic review methodology in the electronic databases PubMed, PsycINFO, Web of Science (WoS) and Scopus. The search date was recorded and all studies identified up to this time were included no matter their date of publication. The grey literature database OpenGrey and the internet were also searched. Our search strategy was designed to be broad enough and sensitive enough to ensure that we captured all potentially relevant studies (Table 1).

In addition to a highly sensitive electronic search strategy, we employed other lateral searches which can be helpful in identifying observational and qualitative studies [17]. These included: (i) checking the reference lists from primary studies and systematic reviews ('snowballing'); and (ii) citation searches using the 'Cited by' option on WoS, Google Scholar and Scopus, and the 'Related articles' option in PubMed and WoS ('lateral searching').

3.3. Eligible studies, inclusion and exclusion criteria

The aim of this review was to explore, in detail, factors associated with the QOL of family carers of people with dementia. The review included quantitative, qualitative and mixed-methods articles that explored this relationship. Only original articles were included. Reviews, commentaries, editorials, conference proceedings, validation and developmental studies were excluded. We excluded interventional studies from this review, as we predicted that the mechanism in which the intervention might impact carer QOL would complicate the interpretation of findings and limit the

clarity of inference possible. The relationship between an intervention and carer QOL would be likely be opaque as it was unlikely to be the primary outcome. Included quantitative studies were required to use and report validated measures of generic or disease-specific QOL. Similarly, factors that were compared with carer QOL were required to be measured and reported using validated instruments.

Qualitative studies were limited to those reporting in-depth individual interviews and focus groups that explicitly asked family carers of people with dementia what they considered important to their QOL or how their QOL had been affected by caring for someone with dementia. All studies included in this review were required to have a sample, or subsample, of family (i.e. family or friend) carers of people with dementia. We did not exclude carers on the basis of the characteristics of the person they cared for (e.g. dementia severity, subtype). We did however exclude studies that covered formal (i.e. paid) carers only, as their motivations and relationship to the person with dementia will be different from those of family carers.

3.4. Study selection

Electronic search results were downloaded into Mendeley™ bibliographic software, where duplicates were deleted. A pragmatic strategy of combining auto- and hand-searching methods of identifying duplicates was employed [18]. Two reviewers (NF & TP) screened titles and abstracts independently against the predefined inclusion and exclusion criteria. Full manuscripts were sought for all potentially relevant studies. All disagreements concerning inclusion were resolved by a group discussion and input by a third researcher (SD).

3.5. Quality assessment

We used the Mixed Methods Appraisal Tool (MMAT) which was specifically developed for mixed methods reviews [19]. This appraisal tool calculates the quality score of a study by dividing the number of positive responses (presence of criteria scored as 1) by the number of “relevant criteria”

× 100. The benefit of this tool is that it makes no value judgement on the relative merits of quantitative versus qualitative methods [19]. Two independent reviewers (NF and TP) scored eligible studies using this tool. Disagreements in scores were resolved through a group discussion and input from a third researcher (SD). At present there is no consensus or empirically tested method for the exclusion of non-interventional quantitative studies and qualitative studies from reviews on the basis of quality alone, however to ensure that low quality studies did not bias the findings, we excluded any study that failed either the MMAT screening questions or scored 25% or lower on the MMAT.

3.6. Data extraction

Data were extracted independently by two authors (NF & TP) for all studies that met the inclusion criteria. These data were entered into a pre-designed form, which was then piloted. Data extracted included data source, study setting, sample characteristics, objectives, and design. Research assistants subsequently confirmed the accuracy of the data extracted. Outcome measures, the QOL measure used, and results (related to factors affecting carer QOL) were extracted from quantitative outcomes. In order to gain consistency in results extracted, we used univariate and bivariate results when presented. If relevant information was not presented sufficiently in the identified articles, it was deemed “Not Reported”. We did not approach the authors for clarification. Themes identified by original manuscript authors and findings were extracted from qualitative studies.

3.7. Synthesis

A narrative synthesis method was used to describe the results, and followed the general framework set out by Popay and colleagues [20]. The results section was divided into thematic headings of independent factors that affect, or do not affect, the QOL of family carers of people with dementia. Themes were identified using an inductive approach, driven by the reported outcomes in the results sections of the included articles. Initially, themes from relevant qualitative studies were extracted.

Two authors (NF & SD) then reviewed articles to determine which quantitative outcomes had been compared to carer QOL. These outcomes, regardless of significance, were grouped independently into subthemes and then themes by the two authors. A carer with lived experience of being a family carer of someone with dementia reviewed the themes identified (TB).

Two authors (NF & TD) reviewed the data independently from the included articles, and identified factors that were related or unrelated to carer QOL (as determined by a threshold of $p < 0.05$).

Where possible the relationship between independent factors and the total carer QOL score was entered into a table. If QOL subscales (and not the total score) were reported in the article, these were also included as long as these subscales had face validity; additional notes were made in these circumstances. A summary code was used to describe the amount of evidence supporting an association for each factor in accordance with previously established methods [21,22]. Symbols were employed to represent positive (+) or negative (-) relationships. We calculated the percentage of studies supporting each relationship by dividing the number of studies that found a relationship by the total number of studies that investigated that factor. As in previous reviews [22,23], a 'summary of association' decision was used: unrelated (0-33% of studies supporting association); unclear (34-59% of studies supporting an association); or related (60-100% of studies were associated).

4. RESULTS

4.1. Study selection

The search was conducted on the 12th November 2015; 1,919 articles were identified using our search strategy. After automatic and manual deduplication, the titles and abstracts were screened for 909 articles identified. Of the abstracts screened, 104 articles were deemed potentially relevant and therefore full-texts were obtained. We were only unable to access a single full-text article [24], which could not be identified or obtained through traditional methods (i.e. inter-library request,

online searches). The article itself, and the journal volume, did not appear on the publisher's website. We were unable to locate the authors' contact details to request the full-text directly, however as the article was published in supplementary material, it is unlikely the content would be relevant for this review. After reading the full-texts of 104 articles, 46 articles were found to meet the inclusion criteria. An additional 8 articles were identified through snowballing and lateral search techniques. See Figure 1 for the flow chart of the review process and reasons why articles were excluded. Descriptive data were extracted from the 51 studies (54 articles).

4.2. Participant and study characteristics

Of the 51 studies (participant n= 10,510), three were qualitative [25–27], one was mixed-methods [28], and the rest were quantitative in design. Participants were recruited internationally, with the United States (eight studies), Australia (four studies), Brazil (four studies) and Netherlands (four studies) being the most common countries for recruitment. Only a single study conducted research across multiple countries [29,30]. Overall 5,332 carers were female and were most often spouses or children of the person with dementia. The care recipients in the studies had a diagnosis of Alzheimer's disease (23 studies), non-specific dementia (17 studies), dementia with multiple pathologies (nine studies), young-onset dementia (one study) and frontotemporal dementia (one study). In the quantitative studies, carer QOL was measured using a number of outcomes, the most common being the SF-36 (14 studies), QoL-AD (10 studies) and SF-12 (seven studies). For a full description of the studies see Appendix A.

4.3. Risk of bias across studies

Many studies did not report in sufficient detail the methodology used and therefore it was unclear whether there were sources of bias in the studies. Six studies scored 100%, 15 studies scored 75%, and 20 studies scored 50% on the MMAT. 10 studies scored 25% or less on the MMAT, and thus were excluded from this review. It is important to note that the MMAT score reflects the authors'

own reporting of the methods used, and may not represent the actual quality of the study. For MMAT scores for each study see Appendix A.

4.4. Narrative synthesis

The remaining 41 studies (participant n=5,539) were included in the narrative synthesis. Of the 41 studies, the studies originated from Europe (n=25), North America (n=5), South America (n=5), Asia (n=3), and Australia (n=3), with no studies from Africa. After extracting themes from qualitative studies and identifying common themes amongst independent variables from quantitative studies, we developed 10 themes. A table outlining the 10 themes and characterising the key findings for each is provided in Appendix B. These themes were:

1. Demographics
2. Carer-patient relationship
3. Dementia characteristics
4. Demands of caring
5. Carer health
6. Carer emotional wellbeing
7. Support received
8. Carer independence
9. Carer self-efficacy
10. Future

4.4.1. Demographics

The nature of the quantitative studies identified meant that demographic information, on both the carer and the person with dementia, was commonly compared to carer QOL. Across all the quantitative studies there was no strong evidence to suggest that the demographic characteristics of

either the carer or the person with dementia impacted on carer QOL. Factors including carer gender and marital status, and the age and education level of the person with dementia, all appeared to be unrelated to carer QOL [31–33]. Data were less clear on associations between carer QOL and carer age, carer education, person with dementia gender, and person with dementia marital status. However, there was emerging evidence that the living situation of the person with dementia and their carer may impact carer QOL, though the evidence is limited. Carers that lived with the person they cared for had poorer QOL compared to those that did not [31]. Perhaps paradoxically, there was also evidence that family carer QOL was poorer where people with dementia lived in a care home, or had had a care home placement in the past 12 months [34,35]. The findings are likely to reflect that the living situation of a person with dementia alone does not inform us of the reasons why the person with dementia does not reside with the carer. Indeed, living situation is likely to be a proxy for a number of factors including disease severity, neuropsychiatric symptoms, functional impairment of the person with dementia, and carer factors (e.g. coping style or ill-health).

4.4.2. Carer-patient relationship

The importance of the relationship between the carer and the person with dementia emerged from the quantitative literature. The literature surrounding this theme is sparse, with the predominant factor explored in studies being whether the type of relationship between the carer and the person with dementia (e.g. spouse [not defined by marriage but incorporating those married or not and whatever the gender relationship], child) influences carer QOL. Two studies found that being a spousal carer was associated with worse carer QOL, compared to offspring who cared [31,36]. This may be confounded by co-residence or not of the person with dementia and the family carer. A single study found carer emotional closeness impacted on carer QOL, as measured by the mental health component of the SF-12 [37]. Only one study examined sexual satisfaction in spousal carers, and it was found to be unrelated to carer QOL [38].

Within the qualitative literature, one study identified that perceived change in relationship was seen to be an important determinant of carer QOL [25], with the change in the ability to communicate with the person with dementia described as upsetting. However, this was not identified as a key theme in the other qualitative studies [26,27].

4.4.3. Dementia characteristics

A common theme identified in much of the qualitative literature was that the health of the person with dementia is seen as a vital determinant of carer QOL [26,27]. Quantitative literature in part supports this, with unmet medical needs being related to carer QOL [39]. This is however a single index of health, and is not synonymous with disease progression. The majority of the literature finds no association between carer QOL and severity of cognitive impairment [31,33,38,40–44] or global severity [43–46]. Interestingly, the duration of the disorder and age of onset were generally related to carer QOL [33,35]. With younger onset and longer duration of disease being related to better carer QOL.

Functional impairment of the person with dementia, which is a predictor of carer burden [46], was frequently reported as being negatively associated with carer QOL [31,36,38,41,42,48,49]. However a number of studies found no such association [32,33,40,50], making it unclear whether there is a relationship between these factors.

In the literature reviewed, we found indications that it may be the symptoms of the disease, in particular comorbidities, which are associated with carer QOL. A single study identified that carers of people with Lewy Body Dementia had a poorer QOL compared to those with AD [51]. This could be due to the presence of hallucinations which are common in the disease. This is supported by the relationship between behavioural and psychological symptoms in dementia, with studies generally finding a negative association [31,42,48,51], though this is not consistent [33,38,41,42,50].

Several studies have identified that carer QOL is interlinked with the QOL of the person with dementia [31,33,38,49]. This is a fundamental finding since QOL is a broad and holistic measure of the life experiences of the individual. However, caution should be taken in the interpretation of these findings, particularly if they use proxy-reports of the QOL of the person with dementia. Carers may project their assessment of their own QOL and health state into their assessment of the person with dementia [53]. In one study the authors found that there was no relationship between carer QOL and patient-reported measures of QOL of the person with dementia, but there was a relationship with carer-reported QOL of the person with dementia [41].

The final factor identified under this theme was the person with dementia's awareness of the disease, with a negative association being reported between impairment of insight and carer QOL in all studies that measured this outcome [38,49]. This finding is also supported in a qualitative study, which found that carers want to be recognised for their caring role [25].

4.4.4. Carer health

A number of factors identified were related to carer physical and mental health, termed here 'carer health status'. Carer depression was the most common factor associated with low carer QOL. Apart from a single study [48], carer depression was consistently found to be negatively associated with carer QOL [31–33,41,43,44,51,54,55]. Carer anxiety was only explored in two studies, but it too was found to be negatively associated with carer QOL [33,56]. Impairment in carer mental health, physical health, health in general and sleep quality were all negatively associated with carer QOL [44,50,56–59]. No association was reported between carer QOL and daytime sleepiness in the single study that measured this outcome [59]. The observed relationship between carer QOL and health indices may be a function of many of the studies this review using generic health-related QOL measures (e.g. SF-36).

4.4.5. Carer emotional wellbeing

This theme was composed of emotional reactions toward the caring role and was rarely explored in literature. Carer QOL was negatively associated with carer burnout and carer stress [43,56]. The ability to find meaning in caring as well as a sense of coherence was found to be positively related to carer QOL [44,60]. More broadly, it was unclear whether carer satisfaction with life was associated with carer QOL, with one study reporting a positive association [55] and another reporting no such association [54]. However, from the qualitative studies, it was reported that most carers felt some satisfaction and reward from caregiving, which was perceived to improve their QOL [27].

4.4.6. Demands of caring

The theme of demands of caring was composed of subjective carer burden measures (e.g. Zarit Carer Burden Inventory) and objective physical and time commitment outcomes. In all studies that compared carer QOL to subjective carer burden there was a negative association reported [32,33,36,38,50,54,55,60–63].

Conversely, it does not appear that objective measures of carer demand are related consistently to carer QOL. Only two studies identified that objective measures of carer demands, time spent caring [31] and length of time caring [60] respectively, were negatively associated with carer QOL.

4.4.7. Support received

Within the qualitative literature, carers often felt that they did not receive adequate support in general or that the level of support from professionals did not meet their expectations [25,26]. As a result, carers felt that receipt of additional support would improve their QOL [26]. In the quantitative literature, there is little evidence that the amount of support received positively affects carer QOL [36,52], with the majority of studies reporting no association between the two [31,32,50]. However,

receiving support may reflect a restriction in available household resources, with finances dictating the quality and choice of both formal support and healthcare received. Some carers believed that their QOL would benefit from additional financial support [27]. The majority of evidence shows increased carer income to be related to improved QOL [32,60,63].

4.4.8. Carer independence

Carer independence was defined as activities and time not spent on caring duties. The relationship between carer independence and carer QOL has been explored [31,32,48,65] by measuring the activities carers participate in other than caring. Irrespective of the activity measured (e.g. leisure activities, employment, household activities or service to others), the majority of the quantitative literature reports a positive association between carer independence and carer QOL. Qualitative research also supports the notion that carer independence is important to carer QOL. In one qualitative study, it was identified that carers felt their QOL would improve if they could have more time for themselves, away from the person that they are caring for [26]. Other studies reported that carer independence was important in allowing carers to pursue their own interests, potentially activities which they had discontinued due to caring, [25,27].

4.4.9. Carer self-efficacy

Self-efficacy, is the individual's belief that they are able to influence successfully domains that affect their lives [64]. For carers in dementia self-efficacy may be dominated by an individual's confidence in coping effectively with different caring tasks. Few studies have used measures devised specifically to measure self-efficacy, however those that have found a positive association with carer QOL [52,63]. One study found that coping skills were positively associated with carer QOL [63].

4.4.10. Future

Dementia being a neurodegenerative disorder means that the role of the carer is ever changing. Qualitative research has identified that worrying about the future, particularly in relation to disease progression, is perceived as worsening carer QOL [26,27]. No quantitative study has explored whether worrying about the future impacts on carer QOL, however, it is possible that carer anxiety may also capture elements of this theme.

5. DISCUSSION

This systematic review seeks to provide a comprehensive evaluation of factors that are associated with the QOL of family carers of people with dementia, drawing on both the quantitative and qualitative literature. Recognition of the modifiable factors that may improve or harm the QOL of family carers of people with dementia can guide the formulation and delivery of policy, treatment, care and support to maintain good QOL in the carers who play such a vital role in dementia care.

Of the 10 themes inductively identified, better carer health (physical and mental) was most consistently associated with better carer QOL. This is an important finding since this is a potentially modifiable factor and serves to underline the potential value of attending effectively to carer health. Greater carer independence, was also positively related to better carer QOL [31,32,48,65] with the positive finding that carers perceived time pursuing their own interests as beneficial [25,27]. Systems and services should work to maximise carer health and support their independence while still caring. The themes 'carer emotional wellbeing', 'future' and 'carer self-efficacy' all present potential avenues for carer support and quality improvement for carers that would be likely to be also beneficial for people with dementia. Further empirical research is needed to investigate these findings and to test the impact of interventions designed to enhance carer QOL measuring outcomes for the person with dementia as well as the family carer.

This review also identified several themes that are less likely to impact carer QOL, with most demographic factors being unrelated to carer QOL. The only exception was the living situation of carers and the person with dementia, which may underpin a number of other themes such as support received and demands of caregiving. While the level of cognitive impairment or functional impairment of the person with dementia does not appear to impact carer QOL, the health status of the person with dementia and behavioural and psychological symptoms appear to be detrimental. This supports their importance as targets for intervention. Functional impairment is likely to be mediated by coping strategies as well as additional support received, and therefore the subsequent impact on carer QOL may be increased or decreased. The dissociation between objective and subjective burden, is indicative that carer appraisal of the situation and perceived stress is likely to be the important determinant of carer QOL. The relationship between income and carer QOL needs further exploration as its effects are likely to be moderated by the availability and funding of statutory services, as well as the source of the income (e.g. carers allowance, pension) and how income is used for carer support.

Measures of QOL can be generic (ie designed to be used across all disorders and health states) or disease/condition-specific (ie relating to a single disorder or health state). It is apparent from the review that generic-measures of QOL (e.g. SF-36, EQ-5D) are most commonly used to assess QOL in carers of people with dementia. This is in line with a previous systematic review that investigated the types of instruments used to measure carer QOL of people with dementia, which found that all studies used generic measures of QOL [66]. This is problematic as generic measures of QOL may fail to capture disease-specific elements crucial to QOL in that condition and may not be sensitive enough to detect changes in outcome following intervention [67,68].

We identified a number of studies that appear to have used a disease-specific measure of QOL, most commonly the QoL-AD, as a measure of the QOL of the carer of the person with dementia. This is

surprising and the rationale for this is not clear. This tool was not developed in any way to assess the QOL in carers of people with dementia; instead it is a measure of the QOL of the person with dementia [68]. This is not the same thing and it does not appear to have been validated as a condition-specific measure of carer QOL in dementia. Given this, any data from its use to measure the QOL of carers are likely to subject to substantial measurement error. However the use of this instrument in this way is likely to signify dissatisfaction with the generic QOL instruments available and indicate a demand for a condition-specific measure of carer QOL in dementia. This is a clear gap in the literature. We only identified two validated measures of carer QOL in dementia, the CGQOL [70] and the ACQLI [71]. However, these measures are not widely used; they were not used in any of the studies identified in this systematic review. A formal evaluation of the development process of these measures is needed to ascertain whether they are suitable for future use.

This review focussed on capturing studies that investigated factors associated with carer QOL internationally, albeit published in English. Family carers play a vital role in dementia care and support across all countries. Of the 41 studies identified, the majority originated from European countries (n=25), with few studies being reported in North America, South America, Asia and Australia (n<6 each). No studies investigated factors that affect carer QOL in Africa. Only a single study included participants across multiple countries [29,30], and then all countries were European; that study was ultimately excluded due to low study quality. We need cross-national studies of the determinants and improvement of family carer QOL in dementia. There are fascinating differences in supports and systems of care, within and between countries. We may have much to learn from the supports and systems across lower and middle income countries as well as the more developed economies [72].

There are limitations as well as strengths to this review. First, in this review we only searched for non-interventional studies, as we predicted that the mechanism in which the intervention might

impact carer QOL would complicate the interpretation of findings. The relationship between an intervention and carer QOL would be likely to be opaque as it was often not the primary outcome. Second, as many of the studies identified do not have carer QOL as a primary outcome, findings could be incidental. The number of statistically significant associations with carer QOL may have been inflated as correlation matrices were common, without correction for multiple comparisons, so increasing the risk of Type I error. Third, there was heterogeneity between groups, with characteristics of the carer varying between studies. Most carers were either spouses or children and therefore the conclusions made here may not be generalisable to other carer relationships. Heterogeneity and missing information was also common in the characteristics of the person with dementia. Fourth, in an attempt to summarise the findings we adopted a 'vote counting' method. Whilst there is a place for such a method as a synthesis tool [20], one shortcoming of this approach is that it assumes equal weighting to studies that may not be equal (e.g. different sample size). Fifth, given the heterogeneity of the studies reviewed, we did not calculate standardised effect sizes enabling associations to be compared directly between studies. This would be methodologically complex but is an area for further research. Finally and importantly, there is a lack of data on how ethnic and cultural factors might influence carer QOL and its measurement. This is a function of this seldom having been investigated in the literature available, either within or between countries. There is a clear need for more and better research in this fundamental area.

6. CONCLUSIONS

This review identifies that the QOL of carers of people with dementia is a complex construct and is affected by multiple factors. Additional research is needed to explore these factors and carer type in more detail, in well-designed studies that have carer QOL as a primary outcome. The data generated would allow policy makers, service providers and clinicians to promote and maintain good QOL in family carers to the benefit of the carers, those they care for, and society as whole. These themes

can be tested empirically in future research and this might well lead to the combination, change or deletion of themes as well as the generation of new ones. There is a clear need for more cross-cultural research. The lack of an established and psychometrically-sound condition-specific measure of QOL for carers of people with dementia is a clear gap in the evidence base. The findings presented here could provide the groundwork for development of such a measure.

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Table 1: Search strategy terms

Search Terms	
#1 dement*	#7 “quality of life”
#2 alzheimer*	#8 QOL
#3 (#1 OR #2)	#9 QL
#4 carer*	#10 HRQL
#5 caregiver*	#11 HRQOL
#6 (#4 OR #5)	#12 wellbeing
	#13 (#7 OR #8 OR #9 OR #10 OR #11 OR #12)
	#14 informal
	#15 unpaid
	#16 spous*
	#17 family
	#18 (#14 OR #15 OR #16 OR #17)
	#19 (#3 AND #6 AND #13 AND #18)

All results were filtered by English language.

Figure 1: Flow diagram of the systematic review process.

